

Greetings to the esteemed members of the Health and Human Services Committee,

My name is Kathy Rickards, and I reside in Brunswick. I am testifying for LD 1606. I am the parent of a 46-year-old man with intellectual disabilities, medical disabilities, and mental health disabilities. I am now more fearful for his future than at any other time in his life.

The proposed Lifespan Waiver is purported to be a flexible, seamless, and fair allocation of services. The devil is always in the details and unfortunately DHHS has been unable to provide a detailed analysis of how Lifespan will actually work, particularly for people with complex disabilities like my son. This lack of oversight is terrifying for those of us who have family members in the system of care. We agonize over how to ensure quality of life after we have passed. That we have a waitlist of over 2000 individuals seems to imply that we, as a State, accept that people with disabilities can live in homes that put them at risk for neglect, abuse, or exploitation. Nowhere in the proposed Lifespan Waiver do I see a public accounting of the people who languish on a waitlist. So, it is your responsibility to ensure that the Lifespan Waiver is Major Substantive with the oversight of the Legislature to demand accountability for your constituents.

Nowhere in the Lifespan Waiver do I see a "fair allocation" of services for people with complex disabilities. The Lifespan Waiver seems to rely on families to provide housing until they die, at which time the individual is moved to any open bed, no matter the State. This in no way provides housing stability for a population that relies on consistency and known and trusted caregivers. The Lifespan Waiver relies heavily on "natural supports"-which is another way of saying parents will also provide day programming, recreational support, and job coaching. This model will devastate a family's economic stability because parents will be unable to work, unable to collect benefits, unable to access employee healthcare, and unable to provide for their retirement. Individuals with disabilities deserve the same opportunities for independence that non-disabled peers enjoy. Having a parent beside them day in and day out is not a model for growth.

Maine needs a multifaceted, evidence based detailed continuum of care to ensure people with disabilities achieve their greatest potential in the most effective and efficient way possible. The Lifespan Waiver, because of its lack of specificity, fails to meet this standard. I call on you to require the Lifespan Waiver be Major Substantive indefinitely due to its life altering implications. Data collection and transparent sharing of that data is the only avenue to ensure Lifespan is meeting its goals. You have a moral and legal obligation to protect the most vulnerable population in Maine. I look forward to working with you and appreciate the opportunity to share my thoughts.